
Cancer Pain Guidelines: Are They Being Used?

Results of a Multi-site Study Conducted by the Hawaii Cancer Pain Initiative

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This study assessed patients' knowledge, experience and satisfaction with their cancer pain management, explored professional documentation and assessment practices and the presence or absence of institutional infrastructures that support pain management. The findings were then compared to the recommended standards and guidelines published by the World Health Organization, American Pain Society and Agency for Health Care Policy and Research.

Introduction

It is well documented that approximately 85% of patients with cancer experience pain during the course of their illness or treatment.^{1,2} The literature also suggests that only 70% of all cancer patients experiencing pain feel that their pain management is effective.³ Studies of pain and patient satisfaction find that patients often rate their satisfaction high even when pain is severe, "suggesting that patients do not expect consistent pain relief and that the use of patient satisfaction questions without other questions about pain ratings may overlook suboptimal pain relief." Hill states that although appropriate opioid analgesics and knowledge about pain is widespread, cancer pain is still widely uncontrolled.⁴ Portenoy believes that undertreatment by practitioners is the primary reason for unrelieved cancer pain although 70% to 90% of this pain can be relieved through pharmacological methods alone.⁵ The World Health Organization (WHO) devised an analgesic "ladder" approach to cancer pain management based on "the premise that most patients...should have adequate pain relief if health care providers learn how to use a few effective and relatively inexpensive drugs well and administer them...according to the individual needs of the patient."⁶ It is estimated that the use of the "three step ladder" devised by the WHO for use in controlling cancer pain effectively controls pain in 71%-97% of patients.⁷ However, with the increasing number of adjuvants and analgesics available for use in different strengths and by different routes, factors such as cost, equianalgesia and patient preferences must be considered when defining a pain treatment plan.

Assessment and documentation are essential for successful pain management, providing the baseline data from which prescribing and treatment decisions are made. The AHCPR Clinical Practice Guidelines for Management of Cancer Pain state that "pain management should be evaluated at points of transition in the provision of services to ensure that optimal pain management is achieved and maintained."² The APS suggests that standardized assessment and communication is the key to successful pain management.⁶ Gathering data and documenting the current status of pain management are important prerequisites to implementing change. Recent studies

show that nurses do not always document patient and family teaching or follow the nursing process which requires assessment and ongoing evaluation of patient care and goals.¹² A recent study in Holland of the effects of a continuing education program on nurses' practice in taking pain histories, performing assessments and managing pain showed an increase in the quality of these activities but not in related quantitative activities such as use of pain rating scales. The nurses participating in the study attributed this phenomena to a lack of support from physicians, varied prescriptive practices, a lack of administrative policies supporting a change in practice and their own reluctance to change their daily routine.¹³ For cancer pain management to become an integrated standard of practice "the challenge of implementation requires involvement by many individuals within the institution."⁸ Since the majority of cancer patients in Hawaii receive their primary and secondary treatment in Honolulu, the importance of standardizing education, assessment and documentation cannot be underestimated.

The research questions this study addressed include:

- 1) Is there a significant relationship between patients' level of comfort, knowledge about and satisfaction with their pain control?
- 2) Is the WHO Analgesic ladder in widespread use?
- 3) Are the recommendations from the AHCPR and APS guidelines for assessment and documentation reflected in current procedures, policies and practices?

Methodology

This study was conducted over a one-year period in seven major medical centers on the island of Oahu. The Institutional Review Board of each medical center approved the study. Primary data was gathered using a patient questionnaire, chart review and an institutional audit tool. The questionnaires were systematic adaptations of tools from the City of Hope Medical Center and used an analog scale to assess patients' level of pain or agreement or disagreement (0-10; 0 = disagree, 10 = agree) with professional beliefs about cancer pain and its management. Each co-investigator was trained in the use of the tools, in assessing a patient's ability to use the questionnaire and in obtaining a signed consent to participate. Each questionnaire took approximately 15 minutes to complete. Any patient concerns or questions about pain that arose as a result of this study were reported to the participant's physician.

The chart review tool was also a systematic adaptation of the tool used by the City of Hope Medical Center. This tool was used on the day the questionnaire was administered to evaluate the types and

methods of assessment and documentation that were being used by various professionals and to record the medications that were currently ordered and being used by each patient. The institutional audit form was also a replication of the tool used at the City of Hope Medical Center. It was used only once in each setting to determine if policies, procedures and institutional processes were in place to insure quality pain management.

Inclusion in the non-random sample required participants to speak English, have a primary diagnosis of cancer and they must have been on at least one opioid for non-surgical, cancer-related pain. Due to reorganization of the oncology units in two of the medical centers and a large population of patients who were non-English speaking or unable to participate due to their physical condition, the study failed to meet the expected sample size of 20 patients per medical center. However, a total of 100 attempts were made, 69 surveys were collected and 67 were usable.

Results: Survey and Chart Review

There were thirty-six (36) males and thirty-three (33) females surveyed. While most respondents were between the ages of 40 and 80, three participants were under 30 and two were over 80. Figure 1 illustrates the ethnicity of the respondents. Other data includes when the participants were diagnosed and when their pain began. Table 1 illustrates this information.

Table 1.—Length of Time Participants Experienced Cancer and Pain

When was your cancer diagnosed?	When did your pain begin?
No. pts/%	No. pts/%
a) in last week 3 (4.7%)	a) in last week 2 (3.3%)
b) in last month 5 (8%)	b) in the last month 7 (11%)
c) in last 6 mos 20 (30%)	c) in last six months . 25 (39%)
d) 6 - 12 mos. ago.....9 (13%)	d) 6-12 months.....12 (18%)
e) 1-2 years ago 5 (8%)	e) 1-2 years ago.....0
f) 2-3 years ago 7 (11%)	f) 2-3 years ago.....3 (4.7%)
g) 3-5 years ago.....8 (12%)	g) 3-5 years ago.....6 (9%)
h) >5 years ago.....6 (9.5%)	h) >5 years ago.....4 (6%)

*Four surveys were unanswered

Participants were asked to fill out a survey that rated their experience with pain over the last week, the last twenty-four hours and at the time of the survey. Respondents diagnoses and the responses to the pain experience questions are illustrated in Figures 2, 3, 4 and 5. All but six of the participants were outpatients during the week prior to the survey. Twelve patients (17%) were receiving radiation therapy, 29 patients (43%) were receiving chemotherapy and 41 patients (39%) were receiving no active cancer treatment. Patients were also asked to rate any side effects of opioid analgesics that they might be experiencing such as nausea, constipation and/or drowsiness. Analog scales were used for all of the ratings (0=none; 10=worst possible). Table 2 illustrates the responses to these questions.

Table 2.—Respondents' Experience with Side Effects

* Rating scale:	0-3	4-6	7-10
<u>No. of patients</u>			
Do you have a problem with constipation?.....	36	13	14
Do you have a problem with nausea?.....	45	11	9
Do you have a problem with drowsiness from your medications?.....	37	20	9

* 0-3=none to mild; 4-6=moderate; 7-10=severe

Patients' knowledge and beliefs about cancer pain and its management were also assessed to see if they agree with current beliefs among health care professionals about cancer pain and its management. Participants were asked to respond using a 0-10 analog scale (0=disagree; 10=agree) to statements professionals generally believe to be true. The responses, showing patients' agreement or disagreement with these statements, are illustrated in Table 3.

Table 3.—Respondents' Knowledge and Beliefs Regarding Pain and Pain Control

	Disagree 0 - 3	Unsure 4-7	Agree 8-10
<u>Knowledge Statements</u>			
Cancer pain can be relieved (7 unanswered)	1	21	37
Cancer pain medicines should be taken before pain becomes severe	8	9	49
It is alright to take more than one type of pain medicine	9	19	25
It is better to take pain medicine around the clock rather than only when needed. (3 unanswered)	16	18	19
Are you satisfied with the treatment you are receiving for pain (3 unanswered)	4	15	45

A concurrent chart review was performed for each respondent to look for the absence or presence of practices that adhere to established standards or guidelines. The chart review specifically looked for consistent use of a pain rating scale, consistent assessment, documentation and prescriptive practices during the time period of the survey, i.e., the twenty-four hours during which the survey was given to the patient to complete. Subjective descriptions of pain, such as, "I feel better today" or "patient states pain continues", were found in 41 respondents' charts. Objective descriptions, specifically analog pain ratings, were found in 50 of the charts reviewed (n=67). As Figure 6 illustrates, assessment and documentation of pain ratings vary widely between disciplines and within the patient's record.

Table 4.—Number of Opioids/Adjuvants and Routes of Administration

Number of patients on one opioid	8
Number of patients on PCA	18
Number of patients with parenteral analgesics and oral opioids/adjuvants ordered	22
Number of patients with more than three routes ordered (IM, oral, transdermal, rectal, IV)	42
Number of patients with more than three medications from the same class ordered	17

Table 4 shows that many respondents had multiple medications ordered by multiple routes. This may have influenced patients' ability to name their medications. Only twenty-six (38%) of those surveyed could name one of the medications they were taking for pain. Eleven respondents (16%) could name two or more medications, however, the remaining patients stated that they could not name their pain medicines.

The responses to the experience and knowledge questions are of interest when coupled with the barriers to pain control that patients themselves identified (Figure 7). While it seems understood that insurance will cover all or most of the costs of hospitalization, it is obvious that patients were also thinking about barriers outside of the acute care setting, where outpatient medications, Patient Controlled Analgesia (PCA) or other therapies are not wholly or partially covered by insurance.

Patients also indicated that they use many alternatives to pharmaceutical pain control methods. Figure 8 illustrates that over half (53%) of those surveyed consider prayer an alternative therapy, while Healing Touch, relaxation, heat and imagery were used as well. One patient stated that he used marijuana and beer, another indicated that music helped and a third indicated that concurrent chemotherapy had relieved some of his pain. Thirty-seven respondents (55%) of those surveyed indicated that they would be willing to use alternatives, twenty-two (32%) respondents indicated they were undecided while only four (5.9%) stated "no" to this option.

When asked to identify health care team members, other than their physician or primary nurse, whom they felt were helpful in controlling their pain, 41% of those surveyed responded "none". Respondents from institutions with formal pain teams indicated that those teams had been helpful as indicated in Figure 9. Patients listed family, self, and friends in the "Other" category.

A nonparametric measure of association between variables, the Spearman rank-order correlation coefficients were computed for the experience (pain and side effect) questions and the knowledge statements. In general, there were significant positive correlations between some of the questions within each group. Only the statement "Cancer pain can be relieved" showed a significant positive correlation with patients' satisfaction with their current pain management ($r_s=0.55$, $p<.001$). There was a small but significant negative correlation between the amount of pain patients were experiencing at the time the survey and their satisfaction. ($r_s=0.29$, $p=0.02$).

A mean pain experience score was computed for each patient summing the responses to the questions "How much pain do you have right now?" "How much pain have you had over the last

twenty-four hours?" and "How much pain did you have in the last week?" and dividing by 3. Similarly a mean knowledge score was computed by dividing the sum of the responses to the knowledge questions by 4. There was a small, significant, negative Spearman correlation between the mean pain score and satisfaction ($r_s=0.34$, $p=0.007$) but no significant correlations between mean knowledge score and satisfaction or between the mean knowledge and experience scores.

Respondents were divided into two groups: those who indicated fear of addiction as a barrier to pain management and those who did not. The responses of the two groups were compared for knowledge, experience and satisfaction. The group that did not identify addiction as a barrier had a higher mean level of agreement with the knowledge questions than those who did. There was also a significant difference in satisfaction with pain management between the two groups ($\chi^2=15.13$, $df=9$, $p=0.040$). The difference between the mean responses to the experience questions was small. The non-parametric Mann-Whitney U (Wilcoxon Rank-Sum) test, which may be used to test whether two independent samples are drawn from the same population, was performed on the mean experience and knowledge scores of the two groups. A significant difference was found between the mean knowledge score of the two groups ($U=210.5$, $p=0.002$), but no statistically significant difference was found between the mean experience scores ($U=436.5$, $p=0.71$). This is consistent with the results of the analysis of the individual knowledge and experience questions.

Findings: Institutional Audit

Four of the institutions participating in the survey completed the institutional audit form, which identified the presence or absence of processes that support effective pain management. Of the four participating institutions, two have a formal pain team in place. All of the responding institutions have admission forms that screen for pain and all have a flow sheet of some kind for pain, although in one instance it is only if a patient is on a PCA. All of the hospitals have equianalgesic charts or other tools available for staff to use. None use caremaps or critical paths nor do they have a specific mechanism to signal ongoing or severe pain, such as incident reports.

Two of the four medical centers require new staff to have or to learn basic pain management principles as part of orientation. The two institutions with formalized pain management teams offer formal educational programs to patients and families and the opportunity for a formal interdisciplinary pain consultation. These institutions incorporate some assessment of patient satisfaction into continuous quality improvement methods. However, the policies that would trigger some type of professional response for unrelieved pain focuses only on patients using PCAs or other invasive techniques, not patients using oral analgesics or other modalities.

Two of the institutions stated that they were involved in ongoing research with regard to pain (not including this study), that costs are an important part of this research and that they have a hotline or consultation service available to outside resources.

Discussion and Recommendations

There were many reasons for conducting this multi-site investigation. Most cancer patients in Hawaii receive their primary and secondary care on Oahu where they may access a variety of different

agencies depending on physician privileges, bed availability and services needed. To date, there has been no aggregate data available to use to evaluate cancer pain management in Hawaii. This study is a starting point for assessing whether professional guidelines regarding pain and its management are being translated into practice.

As the chart review and institutional audit show, prescriptive practices, assessment and documentation vary between settings and practitioners. This is reflected in the fact that patients are not able to identify health care team members other than their physician and nurse as helpful with pain, except where a pain team was available. The majority of those surveyed were also unable to name the medications they were taking for pain. This may have been a phenomena of admission to a facility, where one expects professionals to take the responsibility for the knowledge and management of one's needs. However, the AHCPR and APS guidelines recommend that responsibility for pain management be assigned to "clinicians most knowledgeable, experienced, interested and able to respond to patients' needs in a timely fashion."^{2,6} The AHCPR and APS guidelines also state that patients be informed of the importance of their pain management, participate in their pain management plan of care and that pain be addressed in a collaborative and interdisciplinary manner. Therefore, a strong recommendation is made that institutions designate a person or team that will be responsible for educating patients and staff, as well as designing and evaluating programs that will ensure optimal pain management.

The findings of this study indicate that use of current cancer pain guidelines is inconsistent, as the data shows that patients had orders for multiple opioids and adjuvants in insufficient quantities or by multiple routes. Many participants had multiple medications prescribed from the same "step" of the WHO Analgesic Ladder, i.e., fentanyl patches, PCA and oral morphine. This may be a reflection of inconsistent assessment and feedback or that practitioners are hesitant to order opioids in a large enough dose to control pain. However, it may also be that multiple modalities, including radiation and chemotherapy, were necessary to control cancer pain, which by its evolving nature presents a challenge.

This may account for the fact that one-fourth of the patients surveyed were on IV PCA, one was on subcutaneous PCA and one on intrathecal morphine. This is an interesting finding when one considers that 90% of all patients surveyed were also on oral medications. While it is difficult to quantify the benefit of any given pain control regimen compared with pain relief, all of the current guidelines suggest using the oral route whenever possible with the subcutaneous route as the next alternative. Hospices have used this concept for years in the home setting, with 90% of all patients maintained on oral medications with a high degree of relief and satisfaction.^{16,17} It may be that PCA was being used to determine the appropriate oral dose or patients were being weaned off PCA to other routes. The data is insufficient to determine the reasons for using PCA, however, one questions whether the use of PCA in the hospital was necessary in every case.

Only two of the respondents were admitted solely for pain control so respondents' reports of severe pain in the week prior to the survey leads to many questions. Although 57% of those surveyed experienced pain beginning one to twelve months prior to the survey, the scope of this study could not examine how their pain was being managed during that time. One can only assume that there may be

inconsistencies between outpatient and inpatient pain management related to many variables, including access to services, such as home care or hospice, or reimbursement issues. Further studies are needed in Hawaii to determine how pain is being managed in the outpatient setting. The survey results do indicate that patients are concerned about costs, addiction and side effects and having enough medications "for later" should their pain become worse. The costs of pain management can be quite high, so respondents' anxiety about cost is appropriate, especially for patients on fixed incomes or whose illness may result in a loss of employee health insurance due to an inability to work. A patient in the hospital may have insurance coverage for multiple medications but if these same medications are prescribed on discharge, even the wholesale cost (without a pharmacy markup) can be prohibitive. The major determinants in prescribing pain medicines are a patient's condition, disease status, past pain/drug history, side effects and current response. If there is no physiologic basis for prescribing one drug over another, then costs, availability, cultural biases and other factors should be considered. Professional and community education is needed to extinguish fears of addiction and to increase knowledge about the variety of pain management routes, medications and resources that are available.

The use of PCA and the high incidence of polypharmacy may have influenced patients' responses to the statement "Cancer pain can be relieved." The responses indicate that although pain management experts believe cancer pain can be relieved, this belief is not shared by all of the respondents in this study. The AHCPR and APS guidelines propose that pain be assessed individually, with "relief" defined by the patient's ability to function, sleep, work and otherwise continue their activities of daily living. In other words, achieving a pain rating of "0" may not be the primary goal. One questions whether the inconsistent use of guidelines and apparent lack of participation by patients influenced their responses. Standardizing assessment tools and practices and using easily understood algorithms for prescribing would help clinicians and patients manage pain more effectively.

Anxiety about costs, fear of addiction and undesirable opiate side effects may also influence the responses that show many patients would opt to use alternatives. A mainland study showed patients made "425 million visits to unconventional providers compared with 338 million visits to primary care physicians."²¹ In Hawaii, there are many cultural practices that professionals view as questionable alternatives to Western medicine but that patients consider acceptable. Of interest is the finding that respondents consider prayer an alternative therapy. The impact of spirituality on pain and the use of nondrug interventions would make an interesting subject for further research, particularly in a multi-cultural environment. The use of cold, heat, relaxation, imagery, Healing Touch, distraction and massage may be widespread because they incorporate the "human touch" that contributes to patient satisfaction. Many of these therapies are free or cost no more than \$25, making them cost-effective and attractive to patients. More studies are needed to determine how these therapies can be incorporated into existing health care delivery systems and their impact on the overall cost of pain management.

The factor that was most often identified as interfering with pain control was "having to wait too long for medications." This first relates directly to nursing practices as well as patient education.

Figure 1.—Ethnicity of Respondents

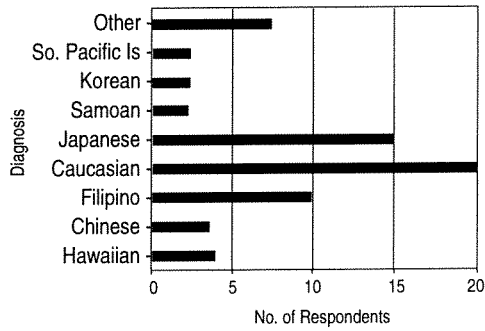


Figure 2.—Respondents by Diagnosis

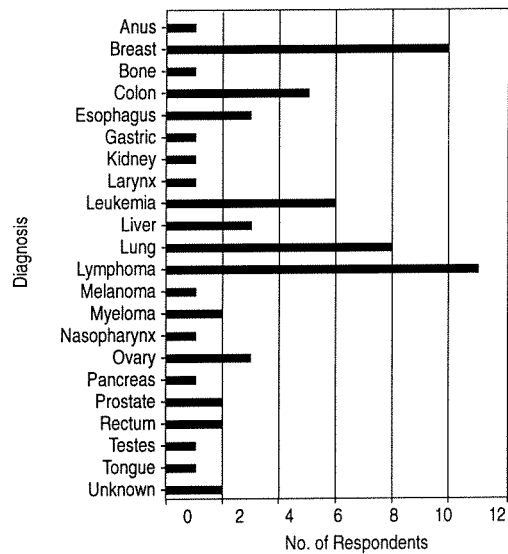


Figure 3.—Patients' Pain Experience in Week Prior to Study

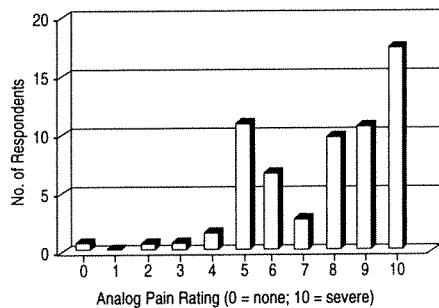


Figure 4.—Pain Experience in 24 Hours Prior to Study

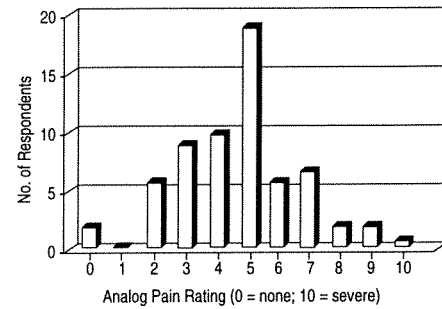


Figure 5.—Patients' Pain Experience at Time of Survey

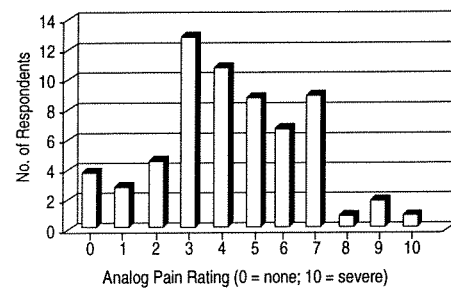


Figure 6.—Documentation of Pain Assessments

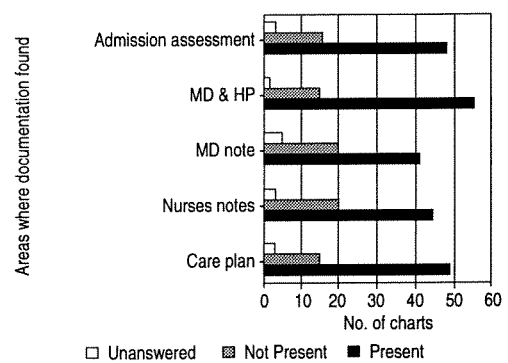


Figure 7.—Patient-Identified Barriers to Pain Control

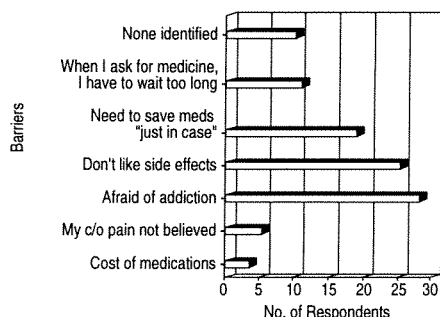


Figure 8.—Alternate Pain Relief Therapies Patients Are Using

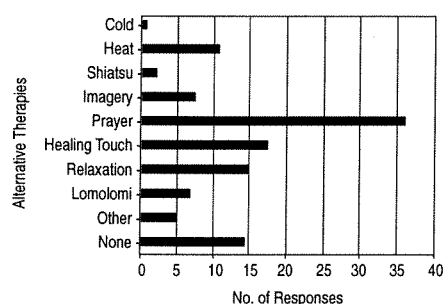
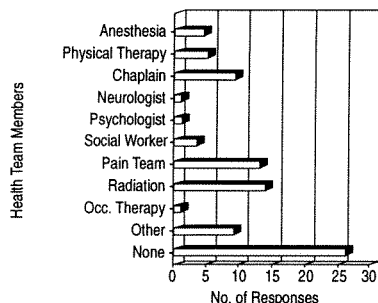


Figure 9.—Healthcare Team Members Identified as Helpful With Pain control



While patients remain on PRN medications, they will still have to ask for their medications. They may also be reluctant to "bother the nurse" or may be uneducated about the need to ask for medication before the pain escalates. This complaint may also be the reason for the use of a PCA pump. One study affirms that the average time it takes for a nurse to deliver an analgesic, including documentation, is 18.42 minutes while others show a waiting time of up to 30 minutes.⁸ This may be due to variables such as staffing shortages that mean a patient's call light is not answered in a timely manner. While this seems to be a minor problem, it

does show that ongoing institutional and professional assessment is necessary to define a standard of practice with regard to pain management.

It appears that some of the guidelines are used part of the time in various ways. While this study cannot show the reasons for inconsistent use of the guidelines, the data does support the fact that there needs to be standardization and further research in a number of areas. The Hawaii Cancer Pain Initiative strongly recommends devising a standardized pain assessment tool and flow sheet that will be used by all medical centers and outpatient agencies. Adopting algorithms that utilize methods of determining efficacy and cost-effectiveness for use when prescribing medications should be considered for use along with the WHO analgesic ladder. All institutions providing inpatient care to cancer patients should have a pain management team or service. If this is outside the resource capability of the agency, then a mechanism for referring to or accessing a pain management resource should be defined. Basic pain management education should be required for graduation from Hawaii's nursing and medical schools. Acute medical centers providing care to oncology patients should mandate competency in cancer pain management for all clinicians working in this area. Recognizing that patients themselves often present many barriers to pain control, research into the educational needs of the Island's various cultural groups, especially validating the use of pain rating tools in other languages, may define culture-specific barriers to pain management. A study comparing outpatient pain management to this inpatient study is needed to provide important information about the needs of cancer patients across the continuum of care. As with any endeavor, these recommendations will require ongoing energy, interaction and commitment from individuals and institutions alike but the benefit to our Island community will be worth the effort.

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